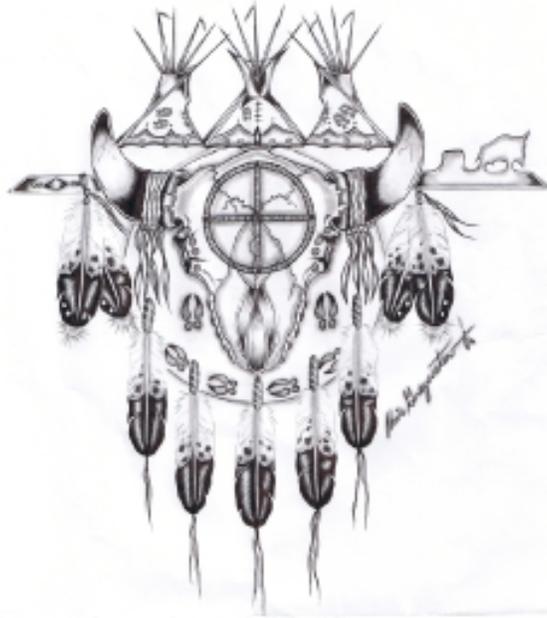


Disability Access Research Utilization Project

Quarterly Report
May, 2007



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Appendix A: Data Collection Instruments

IEP Test and IEP Involvement Form
Information Use Survey
Structured interview questions

Appendix B: Other attachments

Article from the *Turtle Mountain Times*:

Boucher, S. (2007). New technology offers resources to individuals with disabilities and their families. Turtle Mountain Times, 27 (19), 1, 3.

Background

The goal of the Research Utilization Award (RUA) from the Research Utilization Support and Help (RUSH) project is to distribute the results of Disability Access research to a wider audience within Indian country.

Three major activities will take place under this award:

- 1) A multi-method information use survey is being conducted to determine the means by which people with disabilities, their family members and non-disabled tribal members receive information. It is hypothesized that greater use is made of electronic media than generally assumed in the research literature.
- 2) A computer-based training module focused on Individual Education Plans is being developed and evaluated.
- 3) Training demonstrations will be conducted on several reservations not included in the original Disability Access project, and at tribal-focused conferences.

This quarterly report summarizes progress in activity areas of survey design and data collection, plans for information use report, qualitative interviews and preliminary analysis, document collection, IEP Test and IEP involvement form data collection, presentations and articles for tribal journals and short-term outcomes. Data collection instruments are found in Appendix A. These include the Information Use Survey, IEP Test with IEP involvement form and structured interview questions.

Information Use Survey

The information use survey was designed and copies have been distributed on four reservations to date; Turtle Mountain, Spirit Lake, White Earth and Fort Berthold. In the second quarter, data collection will be completed on these four reservations, as well as a fifth, Crow, reservation and at the United Tribes Pow-wow.

A total of 143 surveys have been returned to date, over 90% of these from the Spirit Lake and Turtle Mountain reservations where SLC staff either distributed these personally or contracted with local residents. On Turtle Mountain, where the highest proportion was received, three residents, from two different small communities on the reservation, were asked to conduct the survey in their communities. Volunteers were invited to complete the survey.

On the Spirit Lake Reservation, four residents collected surveys within their local communities. The Spirit Lake Reservation has four communities; St. Michael, Fort Totten, Crow Hill and Tokio. Two of those collecting surveys were from the Fort Totten district, one of whom had many relatives in the Crow Hill district. This is a key factor in the effectiveness of data collection. Although a non-Indian who lives in Fargo would have equal success collecting surveys in Grand Forks, this is not the case on the reservations where we are collecting data. Having a local resident not just from the reservation in question but with ties to that specific community has been crucial in allowing us access to a large sample. Surveys were collected during daytime and evening hours, during weekdays and weekends to minimize selection bias.

Given our prior experience with data collection on the reservations, a concerted effort has been made to use personnel from each reservation, wherever possible. On one reservation (Fort Berthold), the survey is being distributed by both a Head Start project and by a Vocational Rehabilitation staff member. Since Head Start works with families in transition from early intervention and in transition to elementary school, and Vocational Rehabilitation works with adults and youth in transition from high school, these sources allow us to cover the entire age range.

On one reservation, surveys are currently being collected only by Vocational Rehabilitation staff. Dr. Longie will be traveling to this reservation in June to assist in data collection. On other reservations, Dr. Longie has scheduled data collection a few days prior to the pow-wow on each reservation. During these times, it is normative to have many Indians from other reservations visiting, and it is customary to extend courtesy to those visitors, unlike other times of the year when visitors may not be met with the same exceptional hospitality.

During United Tribes Pow-wow in the fall, thousands of Native Americans from tribes throughout the country and particularly the Great Plains, travel to United Tribes. Training workshops are scheduled in the three days prior to the pow-wow. Dr. Longie will be holding an IEP workshop during the pow-wow and collecting surveys from those who attend. This is a deliberately biased sample as, based on the topic, it is expected to be comprised almost completely of individuals with disabilities and their families, which is our group of principal interest. However, as a group who is in town to attend the pow-wow, the

participants are expected to be significantly different in almost all demographics from those who attend the typical conference.

With only half the surveys completed, only preliminary analyses have been conducted to identify any potential problems with the survey, e.g., items left blank, items with extremely low variance. No problems with the Information Use Survey items were discovered. However, there is a disproportion of females among the surveys received to date – 66% are from females. This may reflect the fact that there is a large proportion of female-headed households on the reservations. Few of those requested to complete the surveys refused outright, no doubt reflecting the fact that the data was collected by local community members known to the subjects. The majority of surveys were collected by female staff members and we hypothesized that they may have had a higher response rate from females. Not only were males more likely to refuse to complete the survey, but males may have been less likely to answer the door at all and admit a young female who was not a close relative. To test this hypothesis, in the second quarter, Dr. Longie will travel to four reservations to assist in survey collection. An alternate hypothesis is that, at least on the reservations surveyed to date women may be more likely to participate in volunteer surveys and other civic activities.

We realize it may take more than one visit to each reservation to complete data collection. It is recognized that the reservations may not have the same structure as non-Indian communities. Often, there is not the same degree of participation in support groups, Parent Teacher Associations or other volunteer

organizations that allow for data collection on a group basis. Data collection must occur more at an individual level.

Data from the Information Use Survey will be used to refine our plan for dissemination of information on the Disability Access Project. While, as expected, many participants reported reading the newsletters from Head Start and the public schools, far more than anticipated reported listening to the radio daily or weekly and reading newspapers daily or weekly. As none of the respondents live on reservations with a daily paper, this means that the 38% of respondents reading a daily paper are subscribing to papers off the reservation. Contrary to some stereotypes, many Native Americans take an interest in public affairs at the local, state and national level as well as on the reservation level. In addition, information on tribal members, such as births, deaths, marriages and other news items can be found in the local papers.

Qualitative Interviews

A maximum variation sampling method is being used, with subjects sampled to include people with disabilities, mothers and fathers. Subjects were selected to represent a range of disabilities, from mild to severe and an age range from early childhood through adulthood. Elders with disabilities were not included as they do not fit within the scope of the project.

To date, seven interviews have been completed, with an additional six interviews already scheduled in the second quarter. All interviews have been conducted by a male interviewer who is an enrolled member of the Spirit Lake Nation. In the second and third quarters, three of the interviews will be conducted

by a pair of interviewers, male and female, and three conducted by a female interviewer. The educational level of respondents in the first seven interviews have been significantly higher than the reservation as a whole. This represents a selection effect. Those who have email, cell phones, home telephones and a less chaotic lifestyle are easiest to schedule. Of these first seven interviewees, all had at least a year of college, including two with doctorates, three with bachelor's degrees. In subsequent quarters, interviewees will have a much lower level of education. The seven interviewees had a total of nine children with disabilities, ranging from early childhood through adulthood. Of these, six were adults, two were adolescents and one was a young child. The interviews currently being conducted in the second quarter are predominantly school age children.

In the first interviews conducted, Dr. Longie noted a significant amount of anger expressed by the participants. It was noted that this same angry reaction was experienced by staff members collecting data on an unrelated project on the Spirit Lake reservation, which also questioned parents about their child with a disability. Due to the observed responses, limited follow-up questions were asked to clarify discrepancies as it was perceived that this might harm rapport with the subjects and cause a premature end to the interviews.

It was hypothesized that parents living in poverty with a child with a disability may be angry about the lack of services and the perceived uncaring attitude of disability services staff and project this anger on to the interviewer. It is possible that parents of younger children may have had more positive experiences and have a different emotional reaction. The very limited data to

date does not support that hypothesis. The one mother of a young child interviewed in this first set of interviews, after having the study explained asked early in the interview if the interviewer could just send her the questions in writing and she could submit written answers. At least this one subject clearly did not feel more comfortable discussing her child with a disability than did the parents of adult children.

Document Collection

For cross-validation purposes, documents publicly available on the reservations are being collected by Dr. Longie and two research associates. Documents are being reviewed and analyzed, with the types of disability information provided compared with the information interview respondents state was available to them. To date, documents have been collected from the following organizations:

Spirit Lake Vocational Rehabilitation

Turtle Mountain Vocational Rehabilitation

North Dakota Vocational Rehabilitation – Lake Region

Spirit Lake Even Start

Spirit Lake Diabetes and Fitness

Tate Topa Elementary School

Turtle Mountain Community School Special Education

Turtle Mountain Community College

Cankdeska Cikana Community College

Document collection has been comprehensive. Research associates were instructed to collect copies of “anything that could be picked up or might be given to a client or member of the public”. These include, but are not limited to, the following; brochures describing programs, newsletters from Head Start, elementary school, middle school and high school, client handbooks, flyers posted in offices or waiting rooms, IEP forms, Individual Transition Plan forms, state reports on vocational rehabilitation, newsletters and reports from national organizations and fact sheets from government agencies. Authors ranged from local agency personnel to the National Institute of Health (listed as corporate author).

Although the original intent was to include only paper documents in this analysis, given the Information Use Survey results to date, our data collection has been expanded to include electronic sources. Of the 89 participants to date who gave a favorite site, Yahoo was listed by 39%, far surpassing the next most common sites (msn and hotmail). When entering “American Indian” and “disability” into the Yahoo search engine, six of the first 10 sites referenced the American Indians with Disabilities Technical Assistance Center in Montana (<http://aidtac.ruralinstitute.umt.edu/>). Thus, the publications on the AIDTAC website were downloaded and reviewed also.

Qualitative Data Analysis

We are at the preliminary stages of qualitative data analysis, categorizing excerpts from transcripts and documents and identifying themes. With the limited

data collection to date, a few themes have been tentatively identified. These are as shown below.

THEMES IN INFORMATION USE INTERVIEWS

Informal sources of information

At first diagnosis

After diagnosis

Formal sources of information

At first diagnosis

After diagnosis

Unmet needs for information

Information needs at initial diagnosis

Proactive information seekers

In brief, it appears among those interviewed to date that sources of information differed at initial diagnosis and later time periods. For most respondents, initial diagnosis information came from formal sources such as physicians or the schools. In some cases, the parent was not aware the child had a disability. For example, one mother described how her son originally obtained a diagnosis of a genetic condition that caused mental retardation,

“Dr. ___ (from Indian Health Service) referred us out to Grand Forks and from there they did an assessment and determined what his disability was

and what I had to know and that's when I first that I even knew things like that existed."

Other subjects were aware of a problem but uncertain as to the child's exact condition or needs. A mother of a child who required life-saving medical treatment described being concerned enough about her son's condition that she took him to three different clinics before he received a diagnosis,

"Well, it took a few years because he got sick when he just turned four and he just started swelling and he would eat. I went to (name of Indian Health Service clinic) and they sent us home. I went to (name of second Indian Health Service clinic) and they sent us home. Finally, I took him to (town off the reservation) and the doctor over there found something wrong with his kidney. They did a spinal tap on him."

After the initial diagnosis, in learning about services, a greater use was reported of informal sources. When asked how they learned about the services their children were using now, parents gave some of the following responses:

- *"I had met a parent and one of the children at Turtle Mountain Support Services so that was primarily how I became aware of the program."*
- *"It was word of mouth."*
- *"Word of mouth probably more. Just asking questions of people. Sometimes through the newspaper."*

While the stereotype of Native American parents among school personnel and in the research literature is often that they are uninvolved, this perception is based on parents' lack of attendance at school functions such as parent-teacher

meetings or back-to-school night. In contrast to this stereotype, some of the parents interviewed fit the profile we named “proactive information seeker”.

Examples are given by the following quotes:

- “I got counseling I got services provided to me because I was on TANF. Back then it was called AFDC. I had a girl who helped me get information on what I had to know and learn. I pulled myself together and got rid of the boyfriend who would not support me and I started educating myself. I read anything and everything I could get a hold of. I talked to anybody I could. The school system helped me a lot because by the time he was three they let him go to school and I learned from there. I just kept doing everything possible I could to learn.”

{Interviewer: “Did you look for information about their disabilities on your own?”}

- “Yes I did, I became very familiar with my rights as a parent and I made sure that all my questions were answered.”

As noted above, the first set of interviews included parents who were disproportionately older and more educated than the general reservation population. As data collection continues, these proposed themes will be tested against the new data. Documents collected from agencies are also being analyzed for categorization under the themes identified above or new themes.

IEP Test and IEP Involvement Form

A sign in the St. Michael’s General Store, entitled “How to know you’re an Indian” includes the statement, “You have met five anthropologists before you

turn twenty-one.” The fact behind this humor is that Native Americans, relative to their numbers, are the most-studied population in America. Given this fact, it was the researchers’ decision not to collect data for the Information Use Survey and the IEP Test during the same time period. Further, it was decided to combine the IEP Test and IEP Involvement form into a single measure. From a research standpoint, this will enable correlation of knowledge with involvement and testing of the hypothesis that greater knowledge is related to greater involvement and, on the post-test, that increases in knowledge can result in increased involvement. Pragmatically, most reservations have populations of 6,000 or less. Although people with disabilities are a disproportionate percentage of the population within Native American communities, on most reservations, the total number with disabilities is less than 1,000. Repeatedly requesting the same individuals to participate in surveys and studies is, to put it bluntly, irritating, and likely to have a negative impact on rapport.

We have completed the revision of the IEP Test. All of the multiple choice and short-answer questions were used in tests for computer-integrated training modules under Disability Access or our USDA-funded staff training project, Caring for Our People. A scoring rubric has been developed for the short-answer items. Item difficulty statistics were calculated for all items using a sample of 60 tribal members from the Spirit Lake and Turtle Mountain reservations. All of the items were found to have acceptable levels of variance. The tests from which these items were selected all had adequate internal consistency reliability (.76 or higher) and high inter-rater reliability (> .92). Since IEP-related items from the

various measures have been combined for a new test, it cannot be assured that internal consistency and inter-rater reliability will be equally high, but it is assumed this will be the case. Preliminary psychometric analyses will be conducted after the first 60 tests are collected in the second quarter to allow the opportunity for modifications of the test if necessary.

It was decided to include Information Use Survey questions as page one and the thirteen IEP involvement questions as page two prior to the IEP Test questions. It was further decided to pay each participant five dollars for their assistance with the study.

Presentation at tribal-focused conferences

Staff presented at two tribal-focused conferences during the first quarter. Dr. AnnMaria De Mars and Dr. Erich Longie were exhibitors at the annual meeting of the Consortium of Administrators of Native American Rehabilitation conference in Washington, D.C., during February 2007. During this conference, SLC staff were able to distribute 50 copies of the Disability Access, CD-ROM, provide live demonstrations to over 50 staff members and consumers from tribal vocational rehabilitation projects and distributed over 200 copies of the Miniwakan Tiyospaye newsletter targeting tribal members with disabilities and their families.

SLC staff met with the National Clearinghouse on Rehabilitation Training Materials director. Disability Access is now the first listing on this site under 'new

acquisitions' and will be indexed and included in their digital library (<http://ncrtm.org/>).

There are seventy-three tribal vocational rehabilitation projects in the United States, funded by the Rehabilitation Services Administration to provide vocational rehabilitation services to enrolled tribal members with disabilities who live on or near American Indian reservations. Staff members from the Disability Access RUSH project met briefly with representatives (project directors, vocational rehabilitation counselors or board members) from the majority of these tribal vocational rehabilitation projects. Extended meetings were held with representatives from Sycuan, Fort Berthold, Fort Peck, White Earth, Cheyenne River, Nez Perce, Rosebud, Muskogee, Turtle Mountain and Hoopa Valley. After the conference, Dr. Longie was contacted by the Red Lake Reservation representative who was interested in training but unable to meet with us during the conference. For areas outside of the Great Plains, training is not within the scope of this grant and not offered at the present time, but these individuals were added to our mailing list for our electronic newsletter, provided a CD-ROM and a reference to our website.

Dr. Longie followed up with representatives on reservations within the Great Plains states, has scheduled training on the White Earth, and is currently working with Pine Ridge, Fort Berthold and Crow Agency to set dates for the second quarter.

In April, Dr. Longie presented a workshop at the INMED Advisory Board meeting in Grand Forks to introduce the leaders from 27 tribes to the Disability

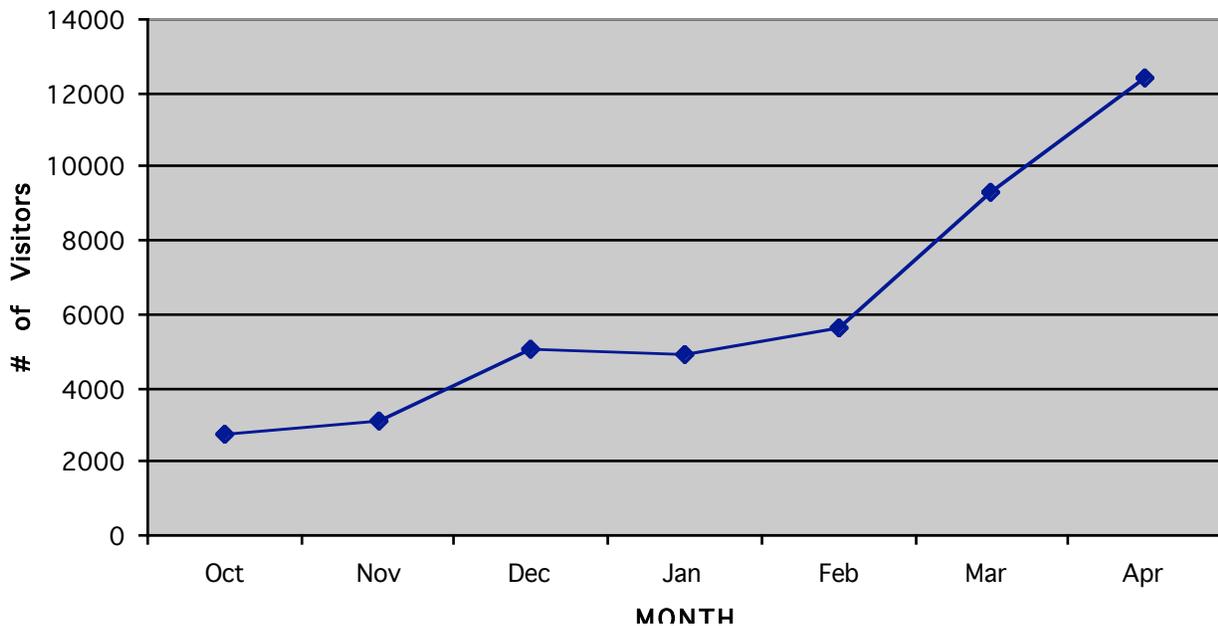
Access project. Indians into Medicine, or INMED, Advisory Board is composed of tribal representatives, appointed by the council, from reservations in North Dakota, South Dakota, Montana, Nebraska, and Wyoming. This organization serves to inform the public of health issues affecting the Indian public, as well as to receive and distribute information about services and opportunities to overall improve the health and welfare of American Indians and provide access to community resources for the reservations. Following this presentation, Dr. Longie received invitations to present the IEP training workshop on the Pine Ridge reservation.

Project staff have also submitted proposals for two additional presentations, at the United Tribes Technical College pow-wow in September, and the CANAR mid-year conference in Savannah, Georgia, in August.

Short-Term Outcomes

While an imperfect measure, one simple means of measuring the

Increase in Website Visitors Coincides with RUSH Funding



effectiveness of Disability Access dissemination is the increase in visits to our website. As can be seen from the chart, a dramatic increase in website visits coincided with the RUSH award beginning February 1. Although one should not infer causation from correlation, this award is the only identifiable new factor during this time period. The project continues to offer workshops on the reservations at the same rate, continues to distribute electronic newsletters bi-weekly. The only significant changes in project operation were all related to RUSH, i.e., presentation at the CANAR conference, distribution of Information Use Surveys, interviews on two reservations, contacting reservation leaders regarding data collection and presentation at the INMED annual meeting.

During the first quarter, Disability Access was the subject of a front-page article in the Turtle Mountain Times (Boucher, 2007). We have also been contacted for an interview on the radio station serving the Pine Ridge Reservation and an interview for the Lakota Times. Both of these will be followed up on in the second quarter. Based on the results to date on the frequency of radio access, Dr. Longie will be contacting KABU radio, which serves the Spirit Lake Nation. While the Disability Access project has sometimes advertised upcoming workshops on KABU, as a result of these data, radio advertising will become a regular part of our dissemination strategy.

Directions for future research

A few of the research challenges met and overcome have been discussed throughout. Data collection, whenever possible, by personnel from the local community, defined on a finer level than 'the same reservation' has enabled us to

collect a substantial number of surveys in a short time period. Use of a Native American interviewer and local contacts has made it possible for us to obtain entry to communities. We have been sensitive to community issues, for example, scheduling the data collection so as not to overlap surveys, combining measures to minimize the number of times community members are requested to assist and allocating a small amount for payments to subjects.

Three obstacles are foreseen in the upcoming quarters.

First, participants have a negative emotional response to questions regarding their family member with a disability. The interviewers have been successful to date in maintaining sensitivity to these feelings, even if it means not asking follow-up questions in some cases. We believe the correct decision has been made in these cases, since, should the participant choose to end the interview, far less information will be collected. The second and third quarter will include interviews with younger parents and with individuals with disabilities themselves. These interviews will also include more interviews by female interviewers and male-female interview pairs. How these differences will affect the emotional tone of the interviews is unknown.

Second, we are concerned about how to maintain anonymity for participants while still providing sufficient information. For example, there are few families on the reservations in question with an adult son with Fragile X syndrome. Hiding the identity of the reservations may be one possibility.

Third, we are concerned about the presentation of information that reflects negatively on those with whom we have personal acquaintances. For example,

some of the documents reviewed could not be useful to any individual with a disability on any reservation under any but the most far-fetched scenario. In some cases, specific interviewers had to be selected because different communities within the same reservation do not get along.

These are the types of information that are important, relevant and may cause problems in our continued research on these reservations if not presented appropriately.

On the positive side, the data that is being collected is unique in many ways. We have been able to survey significant proportions of the population in communities on topics that have not been studied previously. Preliminary results seem to be dispelling some stereotypes about Native Americans and other results are leading to questions which seem likely to open fruitful areas of research.

In the second quarter, data collection on the Information Use Survey and the interviews will continue. We will begin collecting data on several reservations using the IEP Test and IEP Involvement form. The IEP module is nearly complete and Dr. Longie will begin offering workshops next month according to the attached schedule.

**Spirit Lake Consulting Inc.
Master Schedule for Visiting Six Indian Reservations in 2007 - 2008**

RESERVATION	RUSH Progress Report (Mar 1 - May 1, 2007)	RUSH Progress Report (May 2 - Aug 1, 2007)	RUSH Progress Report (Aug 2- Nov 1, 2007)	RUSH Progress Report Nov 2 - Feb 1, 2008)
Spirit Lake	Conduct a multi-method study (interviews & survey)			
<i>Turtle Mountain</i>	Conduct a multi-method study (interviews & survey)			
<i>White Earth</i>		June 18, 2007 Present the IEP module	Conduct a multi-method study (interviews & survey)	
<i>Fort Berthold</i>		Conduct a multi-method study (interviews & survey)		
<i>Trenton Indian Service Area</i>		Present the IEP module		
Sisseton		July 3, 2007 Present the IEP module		
<i>Fort Peck</i>			Present the IEP module	
United Tribes Technical Training College			September 4-7, 2007 Present the IEP module Conduct a multi-method study (interviews & survey)	
<i>Crow</i>			August 13 - 17th, 2007 Conduct a multi-method study (interviews & survey)	Present the IEP module
<i>Standing Rock</i>				Present the IEP module

APPENDIX A: Data collection Instruments

1. IEP Test and IEP Involvement Form
2. Information Use Survey
3. Structured interview questions

IEP Test and IEP Involvement Form

Please tell us about yourself

Name _____ Age _____

____ Male ____ Female

Are you an enrolled tribal member? ____ No ____ Yes

If so, which Tribe? _____

How many years of schooling have you completed? _____

Do you or a close family member of yours have a disability? ____ No ____ Yes

Have you taken any classes from Spirit Lake Consulting, Inc. in the past?

____ No ____ Yes

Have you worked in a job providing services to people with disabilities?

____ No ____ Yes (for how many years? _____)

Do you receive the electronic newsletter from Spirit Lake Consulting, Inc.?

____ No ____ Yes

Do you have an email address? ____ No ____ Yes

If yes, please give your email if you would like to receive the free electronic newsletters: _____

Do you have a computer in your home? ____ No ____ Yes

Can you access the Internet from your house? ____ No ____ Yes

Do you read newsletters from any of the following agencies?

(Please check all that apply).

____ Head Start

____ Vocational Rehabilitation

____ Elementary School

____ Middle School

____ High School

____ Other (Please give us the name _____)

IEP QUESTIONS

Which of the statements below best describes you?

- I may **in the future** be involved in helping to write an Individualized Education Plan (IEP) (either your own or someone else's).
- I am **currently** involved in helping to write an Individualized Education Plan (IEP) (either your own or someone else's).
- I have been involved **in the past** in helping to write an Individualized Education Plan (IEP) (either your own or someone else's).
- None of the above, but I knew about the IEP process through another experience.
- What I know about IEPs I will learn/ have learned through Disability Access training.

Has your child ever had an IEP (Individual Education Plan)?

Yes No I don't know

Has your child ever had an IFSP (Individual Family Service Plan)?

Yes No I don't know

If your child had an IEP or IFSP, did you go to the IEP meeting?

Yes No Not applicable

If you went to the IEP or IFSP meeting, which best describes you?

- A. Just listened and then signed the IEP/IFSP
- B. Asked a few questions, was not happy with 100% of the answers, but signed anyway.
- C. Asked questions and signed the IEP/IFSP when you were satisfied with the answers.
- D. Asked a lot of questions and refused to sign the IE/IFSP until it was changed to meet your concerns.

How often do you use information from these sources in your IEP/IFSP meeting?

	Never	Seldom	Sometimes	Usually	Always
Workshops	1	2	3	4	5
Internet	1	2	3	4	5
Newsletters	1	2	3	4	5
Newspaper	1	2	3	4	5
Radio	1	2	3	4	5
Friends or family	1	2	3	4	5
School or agency personnel	1	2	3	4	5
Other	1	2	3	4	5

Please specify other source _____

True or False

For statements 1 through 12 below, please indicate write "T" in the blank if you think the sentence is 'true' and an "F" if you think it is 'false.'

1. ___ An IEP can be either verbal or in writing.
2. ___ An IEP states all of the following: what the child should be taught, who will teach it, where it will be taught, and how much time this child will spend with children who do not have disabilities.
3. ___ If school personnel thinks it is in the best interest of the child, they can make special education decisions without parental involvement.
4. ___ Under the Indian Education Act, all Native American children have the right to an Individual Education Plan.
5. ___ Parents have a legal right to have school officials listen to their opinions on decisions such as whether or not their child receives special education services.
6. ___ By federal law, each special education student is provided with an Individualized Education Plan (IEP).
7. ___ Students are allowed to attend their own IEP meetings.
8. ___ The majority of learning disabilities are first identified in school.
9. ___ Developmental delay is a label applied when a child is almost certain to be behind his classmates in development throughout his or her life.
10. ___ A client may receive services from both state vocational rehabilitation and tribal vocational rehabilitation.
11. ___ Schools are required to provide transition services to students receiving services under a 504 plan.
12. ___ Research shows that advanced math and science classes are not advisable for students with disabilities due to a high failure rate.

13. An Individual Education Plan (IEP) consists of **(circle ALL that apply)**
- The student's educational goals.
 - The student's family background.
 - Whether the student will have the same graduation requirements as others.
 - Whether the student will be placed in a regular or special education classes.
14. The annual IEP process should be completed by
- The end of the first semester.
 - The beginning of the school year.
 - The end of the school year.
 - Whenever it is convenient for the parties involved.
15. Federal law defines a learning disability as
- Due to social disadvantage.
 - An impairment in neurological functioning.
 - A sensory impairment.
 - A deficiency in social skills.
16. Which of the following is true?
- An IEP may be no more than the child's class schedule and teachers' names.
 - An IEP states how much time this child will spend with children who do not have disabilities.
 - If parents are disruptive, the teacher has the right to hold an IEP meeting without them.
 - Because it may impact their self-confidence to hear themselves being discussed, students cannot attend IEP meetings.
17. Communication disorders
- Only occur in children; they are called articulation disorders in adults.
 - Are almost always the result of the child's inability to hear spoken language.
 - May be greatly improved through a program of speech therapy involving home and school.
 - Have no effective treatment if the disorder is a result of brain injury.
27. Attention Deficit Disorder is characterized by
- Extreme distractibility and impulsive behavior.
 - Attitude problems and below average intelligence.
 - Not being able to sit still and constant lying about bad behavior.
 - Impulsive behavior and aggression against other students.

28. An IFSP is
- A program serving Indian children in foster care.
 - Like an IEP, but designed to meet the needs of younger children.
 - A BIA plan for how school impact aid should be spent.
 - A plan for integrating special education services for children living in foster homes.
29. Full inclusion means that
- All children, no matter how severely disabled, should attend the same early childhood school and community programs as children without disabilities.
 - Children with disabilities should attend school for a full day.
 - The curriculum for children with disabilities should include a full range of activities, both social and academic.
 - Children with disabilities should have the full range of services available from special schools to the regular classrooms.
30. Which of the following statements is TRUE?
- Head Start policy is that sometimes it is in the best interest of children with disabilities to leave them out of certain activities.
 - If any of your students without disabilities feel uncomfortable or disturbed by a disabled student it is best to have the disabled student placed into a class where he fits in.
 - Early childhood education programs have the option of turning away a child with disabilities.
 - Head Start sets aside 10% of slots for children with special needs, regardless of income.
31. Transition services must be included in the IEP
- By age 14.
 - Whenever the student needs them.
 - By age 22.
 - Before the student leaves school.
32. Needs of people with disabilities
- Should be addressed when the disability is identified and then left alone so the person can become independent.
 - Are best met by the individual working it out himself.
 - Change at different points in life as people need to adjust to a disability in childhood, adulthood and old age.
 - Can be determined in early childhood by trained professionals.

33. List two services for which people with mental retardation qualify.
34. Students with learning disabilities usually benefit from
- a. Being educated in a separate classroom for children with LD.
 - b. Being treated the same as other children, with no need for special education.
 - c. Modifications such as longer time to take a test.
 - d. Having lower expectations for them so they don't get frustrated.
35. A person with a learning disability who has trouble keeping a job should
- a. Seek help from vocational rehabilitation
 - b. Ask for accommodations on the job
 - c. Apply for Social Security Disability Income
 - d. Both A and B
36. Your child has been diagnosed with a disability what are some of your legal rights under the Federal law?
37. Name three services that a person with a disability may be eligible to receive under an IEP.

Tanya is 17 years old. She has Fetal Alcohol Syndrome and is the mother of a three-year-old son, Dusty. Tanya quit attending school after the ninth grade when she became pregnant. Tanya lives at home with her mother, her mother's boyfriend and a younger brother. She has never had a job. In fact, when asked, she says that she is not sure she would know how to get one. From the forms she completed, it seems that Tanya reads and writes at about a third-grade level. When asked her goals for the future, she said she would like to be a baby doctor. Dusty is frequently absent from Head Start and has had three ear infections in the last year. His mother often forgets to give him medicine prescribed for these infections.

38. If you were Tanya's mother, what services would you recommend for her?

39. What services would you recommend for your grandchild, Dusty?

40. What type of information is written in an Individual Education Plan? Give three examples, such as, "how many hours of speech therapy a student will receive".

INFORMATION USE SURVEY

Name _____

Age _____

____ Male ____ Female

Are you an enrolled tribal member? ____ No ____ Yes

If so, which Tribe? _____

How many years of schooling have you completed? _____

Do you or a close family member of yours have a disability? ____ No ____ Yes

Have you worked in a job providing services to people with disabilities?

____ No ____ Yes (for how many years? _____)

How often do you listen to the radio?

____ Never ____ Few times a Year ____ Monthly ____ Weekly ____ Almost Every Day

What's the name of the two radio stations you listen to the most often?

How often do you read the newspaper?

____ Never ____ Few times a Year ____ Monthly ____ Weekly ____ Almost Every Day

What's the name of the newspaper you read the most often?

How often do you read newsletters from any of the following agencies?

	Never	Once or twice a year	Monthly	Weekly
Head Start				
Vocational Rehabilitation				
Elementary School				
Middle School				
High School				
Other (Please give us the name) Name:				

How often would you say you read flyers posted around the reservation?

	Never	Once or twice a year	Monthly	Weekly
At the tribal administration building				
In your child's school				
At the tribal college				
At the casino				
In stores or other businesses				
Other (Please give us the name) Name:				

ELECTRONIC INFORMATION

Do you have an email address? No Yes

Do you have a computer in your home? No Yes

Can you access the Internet from your house? No Yes

How often do you use the Internet?

Never Few times a Year Monthly Weekly Almost Every Day

What are two websites you go to often?

How often do you read your email?

Never Few times a Year Monthly Weekly Almost Every Day

Do you receive the electronic newsletter from Spirit Lake Consulting, Inc.?

No Yes

Structured Interview - How Do People Learn About Disabilities

The purpose of these interviews is to find out how people get their information about disabilities and disability services. We would like to know the main sources of your information on disability and disability services and whether or not the types information you receive is helpful.

Personal Information

- 1. Name: _____
- 2. Age: _____ Male: _____ Female: _____
- 3. Are you an enrolled tribal member? Yes _____ No _____
If yes, which Tribe? _____
- 4. How many years of schooling have you completed? _____
- 5. Do you have a computer in your home? Yes _____ No _____
- 6. Can you access the Internet from your home? Yes _____ No _____
- 7. Do you have an Email address? Yes _____ No _____
If yes, write address here (optional): _____
- 8. Have you ever worked in a job providing services to people with disabilities?
 Yes _____ No _____ *If yes, for how many years and what did you do?* _____

Information on Disabilities

- 09. Do you or a close family member of yours have a disability? Yes _____ No _____
- 10. How was the disability discovered (e.g. Family Doctor? IHS Doctor?) _____
- 11. Were you provided with information about this disability? _____
- 12. Describe this disability. _____
- 11. How did you feel when you first heard about your relative's (disability)?

- 12. How did you pay for your relative's medical services? _____

15. Are you aware of any programs that provide services to people with disabilities?

If so, can you name them?

Program

Services Offered

_____	_____
_____	_____
_____	_____
_____	_____

16. What types of services does each of these programs offer?

17. Can you recall how you became aware of this (these) program(s) (radio, newsletter, word-of-mouth, newspaper, posters, etc.; Repeat this for each program.)?

Program

Where you heard about program

_____	_____
_____	_____
_____	_____
_____	_____

17. Where did you get most of your information about services for your disabled relative?

19. Did anyone inform you about rights of your (relative with disability)?

If yes, who informed you about the rights of (your disabled family member)?

20. Where did you get most of your information about rights of disabled persons?

22. Did you look for information about this disability on your own? Yes ____ No ____

If yes, where did you get your information? _____

23. Do you read newsletters from any of the following agencies?
Head Start ____ Vocational Rehabilitation ____ Elementary School ____
Middle School ____ High School ____ Other (please list) _____
24. If you have not been reading newsletters, why not?
Not interested ____ No time ____ Never seen them ____
25. Have there been times when you felt like you didn't have information you needed to care for your disabled relative? Yes _____ No _____
If yes, tell me about one or two of those times.

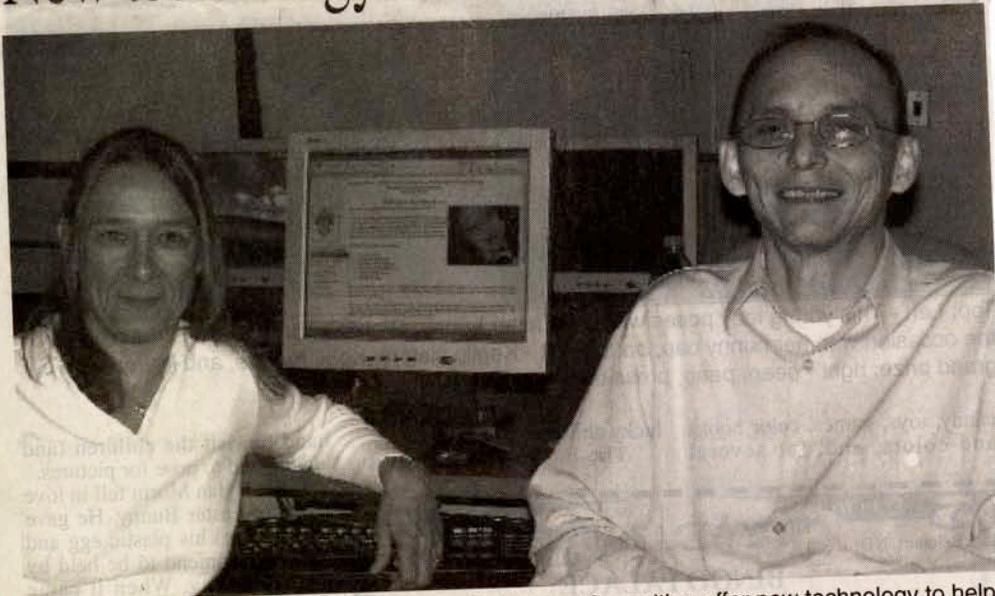
Thank you again for taking the time to participate in this study before I end this interview I want you ask you; do have any closing comments?

APPENDIX B

Copy of Turtle Mountain Times Article

Boucher, S. (2007). New technology offers resources to individuals with disabilities and their families. Turtle Mountain Times, 27 (19), 1, 3.

New technology offers resources to individuals



Dr. Annamaria DeMars and Willie Davis of Spirit Lake Consulting offer new technology to help disabled individuals and their families.

By Susan Boucher
Times Reporter

BELCOURT - With funding

from two grant sources, Dr. Annamaria DeMars, vice-president of Spirit Lake Consulting, along with co-workers Dr. Eric

Longie, Evelyn Klimpel, and Willie Davis, has developed a unique communications site and training program called

with disabilities and their families

Disability Access. Training of the program was held recently at the Turtle Mountain Community College (TMCC) Computer Lab. Assisting Dr. DeMars with the training was Willie Davis, also of Spirit Lake Consulting.

Dr. DeMars was a young widow with two children with special needs. She knows the frustration that comes with parenting a child in a system that is not always parent friendly, much less child friendly, especially when the child has a disability.

With grants dollars from the Department of Agriculture and the Department of Education, Dr. DeMars and her team have developed and produced a "product" as a result of their work. The CD-ROM incorporates the information that has been collected for the Disability Access website. The unique CD-ROM offers students, parents, and anyone who wishes to learn more about disabilities important information. The same information that is on the Access website, but Dr. DeMars and Spirit Lake Consulting know

that not all people have "access" to the Internet.

The information on the website and the CD-ROM will assist disabled students, their families and those that work with either group, with what they need to know to succeed or to help a disabled student succeed.

Davis said that 17 participants attended the two-day training, which received a number of positive comments. Those attending included TMCC instructor Kathy Henry's elementary education students.

The information included in the program explains Individual Education Plans, (IEPs), 504s, and the Individuals with Disabilities Education Act (IDEA) rights, as well as the importance of parental involvement, among many other useful aspects in negotiating with the school system. The system features the actual forms that students and parents can use with the school system.

The site shares "why the laws are important," said Dr. DeMars. She gave an example of a parent

who paid for an assessment of a child, when actually it was the school's responsibility. She said that students have legal rights and that accommodations must be made for the disabled student.

Dr. DeMars said that when people visit a library there is a space provided for reviewing research material. People in rural areas do not have the resource of a large library to research specific disability information. The website and CD-ROM include a virtual library, complete with a "working" fireplace. The library includes articles and literature that deals with disabilities. There are also stories from "real people" who share the knowledge they have learned.

Dr. DeMars added that people in rural areas do not have other parents who have children with the same disability readily available to talk to as happens in larger cities. Disability Access offers a free newsletter as well

SEE: Pg 3A: **TECH**

TECH from pg1

as on-line chatting, and information posted from parents. Dr. DeMars used the example of Traumatic Brain Injury (TBI). In populated areas support groups are held for parents and victims of TBI. With Disability Access even those in rural areas can connect with others who have experience in coping with the disability for support and information. "Every link," said Dr. DeMars, "someone has went through and validated it. It is accurate and up to date." Whether the information was written by one of the staff or printed with permission from a contributor, it has been looked at and approved of by staff of Spirit Lake Consulting.

Regarding children with diabetes, De Mars said there is an 88-page book entitled "How to Prevent Sore Fingers."

People may also write to Spirit Lake Consulting and ask specific questions. The site also allows others to write in with their suggestions, as well. Sometimes the questions come from school staff themselves. "Smaller schools do not have the staff or resources that larger school do," said DeMars.

Eventually the program will be sold for profit, but currently due to the funding that was used to develop the training, the CD-ROMs were free to the training participants. The training workshops have a two-fold purpose. First, is to train people to use the system. Secondly, the training opportunities allow the Spirit Lake Consulting staff to test how the system is working.

Disability Access is all about providing information. Lack of knowledge adds to a stressful situation. DeMars spoke of her daughter's epilepsy, as an exam-

ple. Due to having knowledge about epilepsy and the seizures it can cause has helped DeMars to act calmly and efficiently. Others who know nothing about seizures overreact and panic.

The program also focuses on the "good stuff," said DeMars.

"We tried to think about that mom on the farm," said DeMars of the program development, "or that disabled person on the reservation trying to find a job. It is not about percentages of Native Americans and white individuals with disabilities. That doesn't matter."

Spirit Lake Consulting, "an Indian-owned business," is based out of Ft. Totten on the Spirit Lake Nation. After living in North Dakota for seven years, Dr. DeMars moved to Santa Monica, CA. "The staff would not allow me to quit and leave the company," said DeMars. As a result Spirit Lake Consulting relies on Dr. DeMars "telecom-

muting" to work.

DeMars said that the success of the company has come from each of the organization's staff having a personal interest in what the company is about. In addition to DeMars having had two children with disabilities, she described Dr. Eric Longie as one of the successes of the Vocational Rehabilitation program. Dr. Carol Ann Davis, Belcourt, has also contributed to the company and is a parent to a child with a disability. Willie Davis is noted throughout Turtle Mountain and North Dakota for his advocacy for those with disabilities, in addition to having been nationally recognized.

"Anything," said Dr. DeMars, "unless there is personal interest, will never be as successful."

To learn more about Disability Access or Spirit Lake Consulting, visit their website at spiritlakeconsulting.com.



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